### INSTRUCTIONS FOR COMPLETION OF REM INTAKE/REFERRAL FORM

## Page 1 PLEASE COMPLETE ALL REQUESTED INFORMATION IN INK.

### **Referral Source:**

Referral source name, address, phone number and fax number.

### Patient Information:

Patient's last name, first name, and M.I.

Patient's complete address, including apartment number, if applicable.

Patient's telephone numbers, Medical Assistance number, Social Security Number

Managed Care Organization (MCO) information. This should include the name of the MCO, the name of a contact person and phone number at the MCO.

Patient contact is the responsible party, next of kin, quardian, or significant other.

Please include the contact's complete address, phone number, and relation to the patient.

## Attending Physicians:

Provide the name of the referring physician. Include the physician's specialty, license number, and phone number. The referring physician's signature is **required**. Include any consulting physicians with their specialties, phone numbers, and license numbers.

## Page 2 Complete patient's name and date of birth at the top of page 2.

### Clinical Information:

Provide the primary and secondary diagnoses including the ICD-9 codes. These are necessary to verify eligibility for REM enrollment.

## Supporting Information:

This section will require specific information pertaining to each REM diagnosis. The Medical Intake and Authorization Unit will indicate what information is needed to determine eligibility. Please refer to the diagnostic guidelines as a reference, or call REM for assistance at (1-800-565-8190). Copies of this requested information must be sent in order to review this application.

#### **PLEASE NOTE:**

A physician's signature is required at the bottom of page 2. Please fax this completed form and all supporting clinical information to the REM Medical Intake and Authorization Unit at **410-333-5426**.

### Or mail to:

REM Intake Unit Department of Health & Mental Hygiene (DHMH) 201 W. Preston Street, Room 210 Baltimore, Maryland 21201-2399

For questions please call the Medical Intake and Authorization Unit at (1-800-565-8190).

#### Intake/Referral Form **DHMH USE ONLY** CM Agency: **Rare and Expensive Case Management** Date Assigned: Questions - Call 1-800-565-8190 Screener/Date Fax (410) 333-5426 Mail or Fax To: County **REM Intake Unit** Department of Health & Mental Hygiene (DHMH) 201 W. Preston Street, Room 210 Baltimore, Maryland 21201 Date File Complete: **Approved** Referral Source: Address: Denied **Decision Date:** Phone ( ) Fax ( PATIENT INFORMATION **Patient Name** MA #: Address Home Phone ( ) Apt. # DOB: Work Phone ( ) Sex: State Zip F S S #: City М МСО Contact Person Phone **Patient Contact Contact Phone** Relationship to Patient Address Apt. # City State Zip Code Signature: Date: Referring Physician Phone Name License # Speciality **PCP** Name Phone Speciality License # **Consulting Physician** Name Phone

License #

Speciality

# **REM Intake/Referral Form**

Patient Name:			DOB:	
	CLIN	NICAL INFORMATION	V	
Prima	ry Diagnosis		Secondary Diagnoses:	
ICD-9 Code		ICD-9 Code		
			1	
			2	
			3	
			4	
	SUPPORTING II	NFORMATION (ATTA	CH COPIES)	
History				
Dhysical				
Physical				
Laboratory/Pathol	oav			
,	- 33			
				-
Radiology				
•				
1				
Consultations				
Comments				
MD Signature		Date		

105.5		1	E List as of February 2, 2004
ICD-9 Code	Disease	Age Group	Guidelines
042.	Symptomatic HIV disease/AIDS (pediatric)	0-20	(A) A child <18 mos. who is known to be HIV seropositive or born to an HIV-infected mother and:  * Has positive results on two separate specimens (excluding cord blood) from any of the following HIV detection tests: HIV culture (2 separate cultures)HIV polymerase chain reaction (PCR)HIV antigen (p24)  N.B. Repeated testing in first 6 mos. of life; optimal timing is age 1 month and age 4-6 mos.  or  * Meets criteria for Acquired Immunodeficiency Syndrome (AIDS) diagnosis based on the 1987 AIDS
			surveillance case definition
V08	Asymptomatic HIV status (pediatric)	0-20	<ul> <li>(B) A child &gt;18 mos. born to an HIV-infected mother or any child infected by blood, blood products, or other known modes of transmission (e.g., sexual contact) who:</li> <li>* Is HIV-antibody positive by confirmatory Western blot or immunofluorescense assay (IFA)</li> <li>or</li> <li>* Meets any of the criteria in (A) above</li> </ul>
795.71	Infant with inconclusive HIV result	0-12	(E) A child who does not meet the criteria above
		month s	who:  * Is HIV seropositive by ELISA and confirmatory Western blot or IFA and is 18 mos. or less in age at the time of the test  or  * Has unknown antibody status, but was born to a mother known to be infected with HIV
270.0	Disturbances of amino-acid transport Cystinosis Cystinuria Hartnup disease	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.
270.1	Phenylketonuria - PKU	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required. Lab test: high plasma phenylalanine and normal/low tyrosine
270.2	Other disturbances of aromaticacid metabolism	0-20	
270.3	Disturbances of branched-chain amino-acid metabolism	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note
270.4	Disturbances of sulphur-bearing amino-acid metabolism	0-20	may be required.
270.5	Disturbances of histidine metabolism Carnosinemia Histidinemia Hyperhistidinemia Imidazole aminoaciduria	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.

	Rare and Expensive Disease List as of February 2, 2004			
ICD-9 Code	Disease	Age Group	Guidelines	
270.6	Disorders of urea cycle metabolism	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.	
270.7	Other disturbances of straight- chain amino-acid Glucoglycinuria Glycinemia (with methylmalonic acidemia) Hyperglycinemia Hyperlysinemia Pipecolic acidemia Saccharopinuria Other disturbances of metabolism of glycine, threonine, serine, glutamine, and lysine	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.	
270.8	Other specified disorders of amino-acid metabolism Alaninemia Ethanolaminuria Glycoprolinuria Hydroxyprolinemia Hyperprolinemia Iminoacidopathy Prolinemia Prolinuria Sarcosinemia	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Subspecialist consultation note may be required.	
271.0	Glycogenosis	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	
271.1	Galactosemia	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	
271.2	Hereditary fructose intolerance	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	
272.7	Lipidoses	0-20	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	
277.00	Cystic fibrosis without ileus.	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	
277.01	Cystic fibrosis with ileus.	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	
277.02	Cystic fibrosis with pulmonary manifestations	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	
277.03	Cystic fibrosis with gastrointestinal manifestations	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	

Rare and Expensive Disease List as of February 2, 2004				
ICD-9 Code	Disease	Age Group	Guidelines	
277.09	Cystic fibrosis with other manifestations	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation note may be required.	
277.2	Other disorders of purine and pyrimidine metabolism	0-64	Clinical history and physical exam; laboratory studies supporting diagnosis. Sub specialist consultation	
277.5	Mucopolysaccharidosis	0-64	note may be required. Demonstration of deficient enzyme such as: alpha-L-Idurondase, Iduronosulfate sulfatase, Heparan sulfate sulfatase, N-Acetyl-alpha-D-glucosaminidase, Arylsulfatase B, Beta-Glucuronidase, Beta-Galactosidase, N-Aacetylhexosaminidase-6-SO4 sulfatase.	
277.81	Primary Carnitine deficiency	0-64	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Sub specialist consultation note may be required.	
277.82	Carnitine deficiency due to inborn errors of metabolism	0-64	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Sub specialist consultation note may be required.	
277.89	Other specified disorders of metabolism	0-64	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Sub specialist consultation note may be required.	
284.0	Constitutional aplastic anemia	0-20		
286.0	Congenital factor VIII disorder	0-64		
286.1	Congenital factor IX disorder	0-64	Clinical history and physical exam; laboratory studies	
286.2	Congenital factor XI deficiency	0-64	supporting diagnosis. Sub specialist consultation note may be required.	
286.3	Congenital deficiency of other clotting factors	0-64		
286.4	von Willebrand's disease	0-64		
330.0	Leukodystrophy	0-20		
330.1	Cerebral lipidoses	0-20		
330.2	Cerebral degenerations in generalized lipidoses	0-20		
330.3	Cerebral degeneration of childhood in other diseases classified	0-20	Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Subspecialist consultation note may be required.	
330.8	Other specified cerebral degeneration in childhood	0-20		
330.9	Unspecified cerebral degeneration in childhood	0-20		
331.3	Communicating hydrocephalus	0-20	Clinical history and physical exam; imaging studies	
331.4	Obstructive hydrocephalus	0-20	supporting diagnosis. Sub specialist consultation note may be required.	
333.2	Myoclonus	0-5	Clincal history and physical exam. Sub specialist consultation note may be required.	
333.6	Idiopathic torsion dystonia	0-64	Clinical history and physical exam; laboratory or	

Attachment A Rare and Expensive Disease List as of February 2, 2004 ICD-9 Age Disease Guidelines Code Group 333.7 0-64 Symptomatic torsion dystonia imaging studies supporting diagnosis. Sub specialist consultation note may be required. 333.90 Unspecified extrapyramidal 0-20 Clinical history and physical exam; laboratory or disease and abnormal movement imaging studies supporting diagnosis. Subspecialist disorder consultation note may be required. 334.0 Friedreich's ataxia 0-20 334.1 Hereditary spastic paraplegia 0-20 334.2 Primary cerebellar degeneration 0-20 334.3 Cerebellar ataxia NOS 0-20 Clinical history and physical exam. Neurology consultation note. 334.4 0-20Cerebellar ataxia in other diseases 334.8 Other spinocerebellar diseases 0-20 **NEC** 334.9 Spinocerebellar disease NOS 0-20 335.0 Werdnig-Hoffmann disease 0-20 335.10 Spinal muscular atrophy 0-20 unspecified 335.11 Kugelberg-Welander disease 0-20 335.19 Spinal muscular atrophy NEC 0-20 335.20 Amyotrophic lateral sclerosis 0-20 335.21 Progressive muscular atrophy 0-20 Clinical history and physical exam. Neurology consultation note. 335.22 Progressive bulbar palsy 0-20 335.23 Pseudobulbar palsy 0-20

335.24 Primary lateral sclerosis 0-20 335.29 Motor neuron disease NEC 0-20 335.8 Anterior horn disease NEC 0-20335.9 Anterior horn disease NOS 0-20341.1 Schilder's disease 0-64 Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required. 343.0 Diplegic infantile cerebral palsy 0-20 Clinical history and physical exam. Neurology consultation note may be required. 343.2 Quadriplegic infantile cerebral 0-64 Clinical history and physical examination; supporting imaging studies and neurologic consultation note palsy 344.00 Quadriplegia, unspecified may be required. 0-64 344.01 Quadriplegia, C1-C4, complete 0-64 344.02 Quadriplegia, C1-C4, incomplete 0-64 344.03 Quadriplegia, C5-C7, complete 0-64

ICD 0	Raie and Expensive D		e List as of February 2, 2004
ICD-9 Code	Disease	Age Group	Guidelines
344.04	Quadriplegia, C5-C7, incomplete	0-64	
344.09	Quadriplegia, Other	0-64	
359.0	Congenital hereditary muscular dystrophy	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
359.1	Hereditary progressive muscular dystrophy	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
359.2	Congenital myotonic dystrophy (Steinert's only)	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
437.5	Moyamoya disease	0-64	Clinical history and physical examination; supporting imaging studies and neurologic consultation note may be required.
579.3	Short gut syndrome	0-20	Clinical history and imaging studies supporting diagnosis. Gastrointestinal sub-specialist consultation note may be required.
582.0	Chronic glomerulonephritis with lesion of proliferative glomerulonephritis	0-20	
582.1	Chronic glomerulonephritis with lesion of membranous glomerulonephritis	0-20	
582.2	Chronic glomerulonephritis with lesion of membranoproliferative glomerulonephritis	0-20	
582.4	Chronic glomerulonephritis with lesion of rapidly progressive glomerulonephritis	0-20	Clinical history, laboratory evidence of renal disease.
582.81	Chronic glomerulonephritis in diseases classified elsewhere	0-20	Nephrology sub-specialist consultation note may be required.
582.89	Other Chronic glomerulonephritis with lesion of exudative nephritis interstitial (diffuse) (focal) nephritis	0-20	
582.9	With unspecified pathological lesion in kidney Glomerulonephritis: NOS specified as chronic hemorrhagic specified as chronic Nephritis specified as chronic Nephropathy specified as chronic	0-20	
585	Chronic renal failure  A) Diagnosed by a pediatric nephrologist	0-20	Clinical history, laboratory evidence of renal disease. Pediatric nephrology sub-specialist consultation note may be required.
585, V45.1	B) With dialysis	21-64	Clinical history, laboratory, evidence of renal disease. Nephrology sub-specialist consultation note may be required.
741.00	Spina bifida with hydrocephalus NOS	0-64	Clinical history and physical exam, imaging studies supporting diagnosis. Sub-specialist consultation
741.01	Spina bifida with hydrocephalus cervical region	0-64	may be required.

	Rare and Expensive Disease List as of February 2, 2004			
ICD-9 Code	Disease	Age Group	Guidelines	
741.02	Spina bifida with hydrocephalus dorsal region	0-64		
741.03	Spina bifida with hydrocephalus lumbar region	0-64		
741.90	Spina bifida unspecified region	0-64		
741.91	Spina bifida cervical region	0-64		
741.92	Spina bifida dorsal region	0-64		
741.93	Spina bifida lumbar region	0-64		
742.0	Encephalocele Encephalocystocele Encephalomyelocele Hydroencephalocele Hydromeningocele, cranial Meningocele, cerebral Menigoencephalocele	0-20	Clinical history and physical examination, radiographic or other neuroimaging studies. Neurology or neurosurgery consultation note may be required.	
742.1	Microcephalus Hydromicrocephaly Micrencephaly	0-20		
742.3	Congenital hydrocephalus	0-20		
742.4	Other specified anomalies of brain	0-20		
742.51	Other specified anomalies of the spinal cord Diastematomyelia	0-64	Clinical history and physical examination, radiographic or other neuroimaging studies.	
742.53	Other specified anomalies of the spinal cord Hydromyelia	0-64	Neurology or neurosurgery consultation note may be required.	
742.59	Other specified anomalies of spinal cord Amyelia Congenital anomaly of spinal meninges Myelodysplasia Hypoplasia of spinal cord	0-64		
748.1	Nose anomaly - cleft or absent nose ONLY	0-5	Clinical history and physical examination. Radiographic or other imaging studies and specialist consultation note (ENT, plastic surgery) may be required.	
748.2	Web of larynx	0-20	Clinical history and physical exam; laboratory or	
748.3	Laryngotracheal anomaly NEC- Atresia or agenesis of larynx, bronchus, trachea, only	0-20	imaging studies supporting diagnosis. Sub-specialist consultation note may be required.	
748.4	Congenital cystic lung	0-20	Clinical history and physical exam; laboratory or	
748.5	Agenesis, hypoplasia and dysplasia of lung	0-20	imaging studies supporting diagnosis. Sub-specialist consultation note may be required.	
749.00	Cleft palate NOS	0-20	Clinical history and physical examination. Supporting	
749.01	Unilateral cleft palate complete	0-20	consultation note from ENT/plastic surgery may be required.	
749.02	Unilateral cleft palate incomplete	0-20	roquirea.	
749.03	Bilateral cleft palate complete	0-20		

Attachment A

Rare and Expensive Disease List as of February 2, 2004

CD-9   Disease   Group Code	Rare and Expensive Disease List as of February 2, 2004			
749.20     Cleft palate and cleft lip NOS     0.20       749.21     Unliateral cleft palate with cleft lip complete     0.20       749.22     Unliateral cleft palate with cleft lip incomplete     0.20       749.23     Bilateral cleft palate with cleft lip incomplete     0.20       749.24     Bilateral cleft palate with cleft lip NEC     0.20       749.25     Cleft palate with cleft lip NEC     0.20       750.3     Congenital tracheoesophageal fisula, esophageal atresia and stenosis     0.3     Clinical history and physical exam; imaging studies supporting diagnosis. Sub-specialist consultation note may be required.       751.2     Atresia large intestine     0.5       751.1     Biliary atresia     0.20       751.61     Biliary atresia     0.20       751.7     Pancreas anomalies     0.5       751.8     Other specified anomalies of digestive system NOS     0.5       753.0     Renal agenesis and dysgenesis, bilateral only     0.20       753.10     Cystic kidney disase, bilateral only     0.20       753.11     Polycystic kidney, unspecified supp. Bilateral only     0.20       753.14     Polycystic kidney, autosomal dominant, bilateral only     0.20       753.15     Medullary sponge kidney, bilateral only     0.20       753.16     Medullary sponge kidney, bilateral only     0.20 <td< th=""><th></th><th>Disease</th><th></th><th>Guidelines</th></td<>		Disease		Guidelines
Unilateral cleft palate with cleft lip complete   0-20	749.04	Bilateral cleft palate incomplete	0-20	
Complete	749.20	Cleft palate and cleft lip NOS	0-20	
Incomplete	749.21	· · · · · · · · · · · · · · · · · · ·	0-20	
Rilateral cleft palate with cleft lip   0-20   complete	749.22	·	0-20	
749.24     Bilateral cleft palate with cleft lip incomplete     0-20       749.25     Cleft palate with cleft lip NEC     0-20       750.3     Congenital tracheoesophageal fistula, esophageal atresia and stenosis     0-3     Clinical history and physical exam; imaging studies supporting diagnosis. Sub-specialist consultation note may be required.       751.2     Atresia large intestine     0-5       751.3     Hilrschsprung's disease     0-15       751.61     Biliary atresia     0-20       751.62     Congenital cystic liver disease     0-20       751.7     Pancreas anomalies     0-5       751.8     Other specified anomalies of digestive system NOS     0-10       753.0     Renal agenesis and dysgenesis, bilateral only     0-20       Atrophy of kidney: congenital infamilie Congenital absence of kidney(s) Hypoplasia of kidney(s) Hypoplasia of kidney disease, bilateral only     0-20       753.12     Polycystic kidney, unspecified type, bilateral only     0-20       753.14     Polycystic kidney, autosomal coessive, bilateral only     0-20       753.15     Renal dysplasia, bilateral only     0-20       753.16     Medullary cystic kidney, bilateral only only     0-20       753.17     Medullary sponge kidney, bilateral only only     0-20	749.23	Bilateral cleft palate with cleft lip	0-20	
749.25 Cleft palate with cleft lip NEC 750.3 Congenital tracheoesophageal fistula, esophageal atresia and stenosis 751.2 Atresia large intestine 751.3 Hirschsprung's disease 751.6 Billiary atresia 751.6 Congenital cystic liver disease 751.7 Pancreas anomalies 751.8 Other specified anomalies of digestive system NOS 753.0 Renal agenesis and dysgenesis, bilateral only 753.12 Polycystic kidney, unspecified type, bilateral only 753.13 Polycystic kidney, autosomal dominant, bilateral only 753.14 Polycystic kidney, autosomal creessive, bilateral only 753.15 Renal dysplasia, bilateral only 753.16 Medullary cystic kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only 753.17 Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Sub-specialist consultation note may be required. 753.18 Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Sub-specialist consultation note may be required. 753.16 Clinical history and physical exam; laboratory or imaging studies supporting diagnosis. Sub-specialist consultation note may be required. 753.17 Clinical history, physical examination, radiographic or other imaging studies. Sub-specialist consultation note may be required.	749.24	Bilateral cleft palate with cleft lip	0-20	
fistula, esophageal atresia and stenosis  Atresia large intestine  O-5  751.2 Atresia large intestine  O-5  751.3 Hirschsprung's disease  O-15  751.61 Billary atresia  Congenital cystic liver disease  O-20  751.7 Pancreas anomalies  O-5  751.8 Other specified anomalies of digestive system NOS  753.0 Renal agenesis and dysgenesis, bilateral only  Atrophy of kidney:  congenital infantile  Congenital absence of kidney(s) Hypoplasia of kidney(s) Hypoplasia of kidney, unspecified type, bilateral only  753.12 Polycystic kidney, autosomal dominant, bilateral only  753.14 Polycystic kidney, autosomal recessive, bilateral only  753.15 Renal dysplasia, bilateral only  753.16 Medullary cystic kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only  753.18 Medullary sponge kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only  753.18 Medullary sponge kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only  753.18 Medullary sponge kidney, bilateral only  753.19 Medullary sponge kidney, bilateral only  753.19 Medullary sponge kidney, bilateral only  753.19 Medullary sponge kidney, bilateral only  753.10 Medullary sponge kidney, bilateral only	749.25		0-20	
751.61 Biliary atresia 0-20 751.62 Congenital cystic liver disease 0-20 751.7 Pancreas anomalies 0-5 751.8 Other specified anomalies of digestive system NOS 753.0 Renal agenesis and dysgenesis, bilateral only Atrophy of kidney: congenital infantile Congenital absence of kidney(s) Hypoplasia of kidney disease, bilateral only 753.12 Polycystic kidney, unspecified type, bilateral only 753.13 Polycystic kidney, autosomal dominant, bilateral only 753.14 Polycystic kidney, autosomal recessive, bilateral only 753.15 Renal dysplasia, bilateral only 753.16 Medullary cystic kidney, bilateral only 753.17 Medullary sponge kidney sponge kidney, bilateral only 753.17 Medullary sponge kidney sp	750.3	fistula, esophageal atresia and	0-3	supporting diagnosis. Sub-specialist consultation
751.61 Biliary atresia 0-20 751.62 Congenital cystic liver disease 0-20 751.7 Pancreas anomalies 0-5 751.8 Other specified anomalies of digestive system NOS 753.0 Renal agenesis and dysgenesis, bilateral only Atrophy of kidney: congenital infantile Congenital absence of kidney(s) Hypoplasia of kidney, unspecified type, bilateral only 753.12 Polycystic kidney, unspecified type, bilateral only 753.14 Polycystic kidney, autosomal dominant, bilateral only 753.15 Renal dysplasia, bilateral only 753.16 Medullary cystic kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only	751.2	Atresia large intestine	0-5	
751.62 Congenital cystic liver disease 0-20 751.7 Pancreas anomalies 0-5 751.8 Other specified anomalies of digestive system NOS 753.0 Renal agenesis and dysgenesis, bilateral only Atrophy of kidney: congenital infantile Congenital absence of kidney(s) Hypoplasia of kidney(s) Cystic kidney disease, bilateral only 753.12 Polycystic kidney, autosomal dominant, bilateral only 753.14 Polycystic kidney, autosomal recessive, bilateral only 753.15 Renal dysplasia, bilateral only 753.16 Medullary cystic kidney, bilateral only 753.17 Medullary sponge kidney in the many be required. 753.18 Consultation note may be required. 753.19 Consultation note may be required. 753.10 Consultation note may be required. 753.11 Medullary cystic kidney, bilateral only 753.12 Medullary sponge kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only	751.3	Hirschsprung's disease	0-15	
751.7 Pancreas anomalies  751.8 Other specified anomalies of digestive system NOS  753.0 Renal agenesis and dysgenesis, bilateral only Atrophy of kidney:	751.61	Biliary atresia	0-20	
751.8 Other specified anomalies of digestive system NOS  753.0 Renal agenesis and dysgenesis, bilateral only Atrophy of kidney: congenital infantile Congenital absence of kidney(s) Hypoplasia of kidney(s)  753.10 Cystic kidney disease, bilateral only 753.12 Polycystic kidney, unspecified type, bilateral only 753.13 Polycystic kidney, autosomal dominant, bilateral only 753.14 Polycystic kidney, autosomal recessive, bilateral only 753.15 Renal dysplasia, bilateral only 753.16 Medullary cystic kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only 753.18 Other imaging studies. Sub-specialist consultation note may be required.	751.62	Congenital cystic liver disease	0-20	
digestive system NOS  Renal agenesis and dysgenesis, bilateral only Atrophy of kidney:	751.7	Pancreas anomalies	0-5	
bilateral only Atrophy of kidney: congenital infantile Congenital absence of kidney(s) Hypoplasia of kidney(s)  753.10 Cystic kidney disease, bilateral only  753.12 Polycystic kidney, unspecified type, bilateral only  753.13 Polycystic kidney, autosomal dominant, bilateral only  753.14 Polycystic kidney, autosomal recessive, bilateral only  753.15 Renal dysplasia, bilateral only  753.16 Medullary cystic kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only  753.17	751.8	· · · · · · · · · · · · · · · · · · ·	0-10	
753.12 Polycystic kidney, unspecified type, bilateral only  753.13 Polycystic kidney, autosomal dominant, bilateral only  753.14 Polycystic kidney, autosomal recessive, bilateral only  753.15 Renal dysplasia, bilateral only  753.16 Medullary cystic kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only  753.18 Polycystic kidney, autosomal o-20 only  753.19 Renal dysplasia, bilateral only  753.10 Medullary sponge kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only	753.0	bilateral only Atrophy of kidney: congenital infantile Congenital absence of kidney(s)	0-20	
753.12 Polycystic kidney, unspecified type, bilateral only  753.13 Polycystic kidney, autosomal dominant, bilateral only  753.14 Polycystic kidney, autosomal recessive, bilateral only  753.15 Renal dysplasia, bilateral only  753.16 Medullary cystic kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only  753.17 Medullary sponge kidney, bilateral only  753.18 Polycystic kidney, autosomal o-20 other imaging studies. Sub-specialist consultation note may be required.  753.16 Medullary cystic kidney, bilateral o-20 only  753.17 Medullary sponge kidney, bilateral o-20 only	753.10		0-20	
753.13 Polycystic kidney, autosomal dominant, bilateral only 753.14 Polycystic kidney, autosomal recessive, bilateral only 753.15 Renal dysplasia, bilateral only 753.16 Medullary cystic kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only 753.18 Polycystic kidney, autosomal o-20 other imaging studies. Sub-specialist consultation note may be required. 753.16 Medullary cystic kidney, bilateral o-20 only	753.12	Polycystic kidney, unspecified	0-20	
753.14 Polycystic kidney, autosomal recessive, bilateral only 753.15 Renal dysplasia, bilateral only 753.16 Medullary cystic kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only 753.17 Medullary sponge kidney, bilateral only	753.13	Polycystic kidney, autosomal	0-20	
753.15 Renal dysplasia, bilateral only 0-20  753.16 Medullary cystic kidney, bilateral o-20 only  753.17 Medullary sponge kidney, bilateral o-20 only	753.14	Polycystic kidney, autosomal	0-20	note may be required.
753.17 Medullary sponge kidney, <b>bilateral</b> 0-20 only	753.15		0-20	1
753.17 Medullary sponge kidney, <b>bilateral</b> 0-20 <b>only</b>	753.16	3 3	0-20	
	753.17	Medullary sponge kidney, <b>bilateral</b>	0-20	
	753.5	,	0-20	

Attachment A

Rare and Expensive Disease List as of February 2, 2004

ICD-9 Code	Disease	Age Group	Guidelines
756.0	Musculoskeletalskull and face bones Absence of skull bones Acrocephaly Congenital deformity of forehead Craniosynostosis Crouzon's disease Hypertelorism Imperfect fusion of skull Oxycephaly Platybasia Premature closure of cranial sutures Tower skull	0-20	Clinical history, physical examination, radiographic or other imaging studies supporting diagnosis. Subspecialist consultation note may be required.
756.4	Trigonocephaly Chondrodystrophy	0-1	
756.50	Osteodystrophy NOS	0-1	
756.51	Osteogenesis imperfecta	0-20	Clinical history, physical exam; imaging studies supporting diagnosis. Sub-specialist consultation note may be required
756.52	Osteopetrosis	0-1	
756.53	Osteopoikilosis	0-1	
756.54	Polyostotic fibrous dysplasia of bone	0-1	
756.55	Chondroectodermal dysplasia	0-1	
756.56	Multiple epiphyseal dysplasia	0-1	Clinical history, physical examination, imaging studies
756.59	Osteodystrophy NEC	0-1	supporting diagnosis. Sub-specialist consultation
756.6	Anomalies of diaphragm	0-1	note may be required.
756.70	Anomaly of abdominal wall	0-1	
756.71	Prune belly syndrome	0-1	
756.79	Other congenital anomalies of abdominal wall	0-1	
759.7	Multiple congenital anomalies NOS	0-10	Clinical history, physical exam; laboratory or imaging studies supporting diagnosis. Sub-specialist consultation note may be required.
V46.1	Dependence on respirator	1-64	Clinical history and physical exam. Sub-specialist
V46.9	Machine dependence NOS	1-64	consultation note required.